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The Effects of Visual Stimuli on Conversations in Dementia

A Senior Honors Thesis

Presented in Partial Fulfillment of the Requirements for graduation
with research distinction in Speech and Hearing Science in the undergraduate colleges of The
Ohio State University

by

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CERTIFICATION FOR GRADUATION WITH RESEARCH DISTINCTION

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THESIS TITLE: The Effects of Visual Stimuli on Conversations
in Dementia

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ABSTRACT

Dementia is characterized by difficulty with communication tasks, such as generating ideas and conveying meaning, as well as memory deficits such as word finding difficulties and repetitive behavior (Bourgeois & Hickey, 2009). Memory Books are used as written and graphic cues to support memory and conversation for persons with dementia (Bourgeois, 2007). The purpose of this study was to examine the relative benefits of different types of stimuli found in Memory Books that patients can use in conversation. The questions addressed were: How do different types of stimuli affect the conversations of patients with dementia? Is print alone better? Are pictures alone better? Or does the combination of print and picture stimuli together help the individual to participate in the best conversations?

After receiving consent from a family member, each subject was made three different versions of a Memory Book. One version had only pictures, one only sentences and the last was a combination of the two, all with ten facts, one per page. Three experimental sessions were conducted with each subject on separate days. In each session, the three different books were presented in counter-balanced order to elicit 5 minutes of conversation each. In between each type of book, a 10 minute distraction activity was administered, such as games or puzzles. Data analysis revealed that persons with dementia produced more novel utterances, and other positive conversational features, when using Memory Books with both pictures and text in combination than when conversing with Memory Books consisting of pictures alone or text alone.

INTRODUCTION

Dementia is the deterioration of memory and other cognitive functions specifically outlined as impairment in social and occupational functioning (DSM-IV, 1994). Many degenerative diseases can cause dementia and it is common in the elderly (Bourgeois, 2007). Dementia is degenerative in nature and over time, the individual becomes more impaired (Cummings, 2003). Dementia is characterized by communication difficulties, such as generating ideas and conveying meaning. More specifically, there are also memory issues such as word finding and repetitive behavior (Bourgeois & Hickey, 2009). This often impacts their everyday life, and makes it hard for the family and caregivers to communicate with them about everyday tasks and situations. Individuals experiencing dementia often have trouble finding the words that they want to use in conversation and remembering the answers to questions their caregiver just provided. Memory loss is the primary symptom in those with dementia.

In the earlier stages of dementia, short term memory begins to diminish first and is first noticed by family members and friends. With progression of the disease, long term memory becomes more impaired. Without the ability to save new information from short term memory into long term memory, retrieving memories becomes difficult and negatively impacts quality of life. The use of an external memory aid can be used to help the individual trigger stored long term memories and reduce the frustration experienced by persons with dementia during conversations.

Language and memory are intertwined such that it is difficult to discuss one without discussing the other (Bourgeois & Hickey, 2009). Language is the system of words, meaning, syntax, and pragmatics upon which social communication is dependent. Memory is the process of storing and retrieving thoughts, words, events, and skills that have been learned over one's

lifetime. The two networks work together. For example, word finding difficulties, empty speech (meaningless) and the use of indefinite references (such as ‘thing’, ‘it’) are language abnormalities that result from faulty memory processes (Cummings, 2003). Language can be described as the physical expression of memories. Without the memory of a particular event, a person with dementia may have difficulty conversing with another individual in a satisfying way.

Memory Books are used as written and graphic cues to support memory and conversation. It has been found that the use of Memory Books greatly increases the quality and quantity of conversations in those with dementia (Bourgeois, 2007). Conversation requires the person to retrieve specific words or ideas from memory and to remember the topic of conversation. It is not surprising that it is hard for those with dementia to hold a meaningful conversation with another person without an external memory aid. The purpose of Memory Books is to support and trigger memories that these individuals still have but have difficulty remembering on their own.

Memory Books consist of written sentences and pictures. It had been believed that person with dementia would have reading difficulties. It has been found, however, that the ability to read is preserved in dementia (Bourgeois, 2007). The ability to read stays intact until the later stages of dementia (Bourgeois & Hickey, 2009). Evidence from other Memory Book studies supports the use of written sentences in a memory aid to enhance conversation (Bourgeois, 1992b). The individual with dementia can read the personalized statement in their Memory Book and other related memories are triggered with this form of cueing. Additionally, the memory aid can be modified using a larger print font to maintain the ability to read and retrieve memories as the person’s dementia becomes more severe.

The use of Memory Books is a compensatory strategy. Compensatory strategies are used to get around the memory problem without directly teaching or re-training the information that has been forgotten (Bourgeois, 2007). Memory Books help the individual to generate conversation using the sentences and pictures that illustrate the life and times of the individual and their family by triggering long term memories that are stored in the brain. The use of memory aids is a popular way to address the common types of short and long term memory problems experienced by persons with dementia. For example, persons with dementia have trouble remembering short term memory facts, such as what they went in the kitchen to get. They may also have trouble remembering long term memory facts, like the names of specific family members. A memory aid can be the cue for short term memory and can help them access information stored in long term memory (Baddeley, 1995). Short term memory facts may be helped by another variation of memory aids in the form of cue cards with everyday information such as “We are going to church,” for the person who cannot remember the answer to their repetitive question, “Where are we going?” The Memory Books used in this study mainly addressed long term memory facts.

Another important use of Memory Books is that they can be used to help make the day go more smoothly for the staff at a care facility. Repetitive questions, a short term memory problem, are often asked by individuals with dementia. Instead of answering the question repeatedly, the caregiver can show them a “book,” a page, or a cue card about the topic. When individuals read the answer to their question on their own they appear to understand better and are more accepting of the answer (Bourgeois et al., 1997). Not only is this beneficial to the patient but to the caregiver also. The caregiver feels good that they can improve a situation that was previously frustrating (Bourgeois et al, 1997). Memory Books are designed for the

individual with dementia but they can also help the caregiver communicate with the person with dementia.

The previous research on the effects of Memory Books on patients with dementia involved Memory Books consisting of written sentence and picture stimuli (Bourgeois, 2007). Each memory book page included one sentence or phrase and at least one picture; for example, “I graduated from Pomfret School in 1968,” and the picture of the school building. In previous research, Memory Books included both types of stimuli. It is unknown, however, what specific type of stimulus (print, picture or a combination of the two) contributes the most to the process of accessing memories during conversation. The purpose of originally using a combined stimulus for Memory Books was to give individuals the most potential to access the memory. Understanding the relative benefits of each stimulus is a question that came up after a combined stimulus had been used regularly.

The purpose of this study was to provide important information about the relative benefits of different types of stimuli that patients can use in conversation. The questions asked were: How do different types of stimuli affect the conversations of patients with dementia? Is print alone better? Are pictures alone better? Or does the combination of print and picture stimuli together help the individual to participate in the best conversations? This study determined whether or not there were differences in the amount and type of utterances produced by persons with dementia using Memory Books consisting of different types of stimuli. It was hypothesized that the combination of both print and picture stimuli would yield the best quality and quantity of utterances by individuals with dementia.

METHODS

Participants

Candidacy for participation in this study was determined by the staff of nursing homes in the Columbus area. Requirements included that the individuals must have a diagnosis of dementia and be willing to engage in conversation with another individual. After recommendation from the staff, consent was requested from the family (Appendix A). After consent was established, the researchers visited with the family and the participant to conduct screening procedures. For screening purposes, the *Memory Book Study Protocol* (Appendix B) was administered which included the *Mini-Mental State Examination* (MMSE) (Folstein et al, 1975) and the *Bourgeois Oral Reading Screen* (Bourgeois, 1992a). The purpose of these measures was to document the severity of dementia and the font size (either 36 point font or 14 point font) that could be easily read by the participant. Additional information regarding hearing loss or vision impairment was gathered, either from the participant or a family member/caregiver to confirm that the participant could hear the experimenter and see the materials.

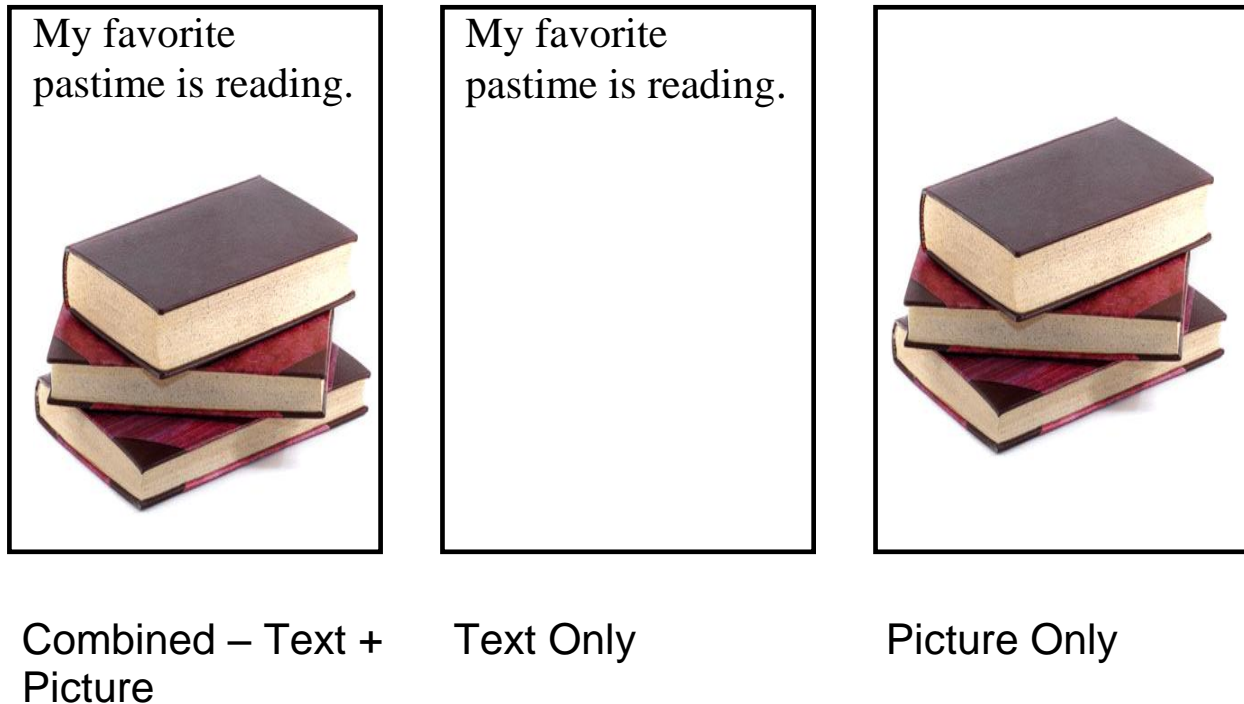
The study involved 6 participants, four females and two males, with a mean age of 85 years (S.D. = 4.6). The mean MMSE score was 17.2 (S.D. = 3.3) indicating dementia of moderate severity. All participants read the 36 point font with fewer than 2 errors.

Materials

Information about and pictures of important people, things, and hobbies in the participants' life were gathered from their family member using the Memory Book Information Form (Section IV of Appendix B). The family photos were photo-copied and returned. The information gathered was compiled into a ten-page memory book consisting of one sentence and one picture per page. Two additional versions of the memory book were made; one that

consisted of the sentences only (one per page) and another that consisted of the pictures only (one per page) as seen in Figure 1.

Figure 1: Samples of the three formats of the Memory Book.



All pages were 8 ½ x 11 inches in size and presented in plastic page protectors. All text was 36 point font. Each version of the Memory Book was placed in a ½ inch black binder.

Setting

Each session was conducted in a quiet room at the nursing home or the family home. The experimenter sat at a 90 degree angle from the subject around the corner of a table. Sitting beside the participant allowed the examiner to turn the page or assist the participant. No distractions, such as the television, were permitted. The rooms were well lit to eliminate the possibility of any vision issues during the sessions.

Design

This study was a within subjects group designed investigation of the effects of three stimulus conditions (combined, text alone, and pictures alone) on multiple conversational utterances in the form of dependent variables or codes. There were six participant codes which included Memory Book Statement, Novel Related Statement, Novel Unrelated Statement, Perseverative Utterance, Error Statement, and Other Speech Act. There were three partner codes which included Partner Prompt, Partner Statement, and Partner Other. See Figure 2 for definitions of these variables.

Procedure

Each participant conversed with the experimenter during three sessions, each of which was approximately 30 to 45 minutes in length. During each session, the three versions of the memory book were presented in a counter-balanced order. The purpose of having a counter-balanced order was to rule out the possibility of order effects. Counter-balancing occurred not only between trials for the subject but also between each of the participants. In between the presentation of each Memory Book, a distraction activity was presented such as a craft or a puzzle. The purpose of this is to clear their mind from the task at hand and prevent recall of specific conversation from the previous trial. Each trial began with the researcher statement,

“I made a book for you. It has pictures (sentences/pictures, sentences) about your life. It can help you talk about your life/family/things that were important to you.”

During the conversational sessions, if the participant did not respond within 5 seconds or stopped talking, the researcher prompted with “Please read this” or “What else can you tell me about that?” The session continued until a stopwatch signaled that five minutes had passed. If the

participant was still talking when the stopwatch signaled five minutes had elapsed, the experimenter waited for a lull in conversation before moving on to the distraction activity. The distraction activity was presented by saying,

“Let’s do something different now. Would you rather do a puzzle or play a game?”

The sequence of Memory book stimulus then distraction activity continued until all three types of stimulus had been presented.

Transcription and Coding

Each session was audio-taped with an Olympus Digital Voice Recorder WS-400S, then later transcribed by the researcher. Each sentence or utterance was numbered and later coded using definitions adapted from Bourgeois (1992). A description of each code is listed in Figure 2. The coding system captured qualitative and quantitative features of the conversation. There were 6 subject behavior codes and 3 partner behavior codes. Using a data coding sheet (Appendix C), the dependent variables in Figure 2 were used to code each sentence from the transcription. After assigning each sentence a code, each dependent variable was counted and tallied at the bottom of the data coding sheet in the appropriate box. The summarized data was entered into an Excel spreadsheet and then analyzed with Repeated Measures ANOVA Analysis using SPSS.17™.

Figure 2: Dependent Variables.

	Participant Codes
M	Memory Book Statement - Must be one of the 10 printed statements <i>read</i> from the memory book. Must be intelligible and unambiguous; exact wording.
NR	Novel Related Statement – Must be an intelligible and unambiguous statement of a fact contributing additional content related to the stimuli presented.
NU	Novel Unrelated Statement – Must be an intelligible and unambiguous of a fact contributing to the conversation that is not directly related to the stimuli presented.
P	Perseverative utterance – Any intelligible utterance that is a repetition of a previously stated novel utterance.
E	Error Statement – Intelligible and unambiguous utterances related to the stimuli that are determined by the caregiver to be false.
O	Other Speech Acts – Including unintelligible and ambiguous statements. Also including statements such as “Okay”, “Oh”, and “Alright”.
	Partner Codes
PP	Partner Prompts – The beginning script for each trial. Also, phrases such as “Tell me about that,” “What else could you say about that?” or “Is there anything else you want to tell me about that?”
PS	Partner Statement – Any utterance that serves to comment upon a participant’s utterance by providing additional content to the discussion.
PO	Partner Other – Any other speech act that serves to regulate the conversation without providing content, particularly acknowledgments and reassurances. Also included statements from others in the environment.

Reliability

Reliability of the data coding was established by recruiting a second coder. The second coder independently learned the definitions of codes that were established by the primary coder. One random transcription was selected for training purposes and was used to verify that both coders thoroughly understood the definitions of the codes. The reliability of the training data was 80% agreement. The secondary coder coded 22% of the data collected, 2 of every 9 transcripts per participant, or 12 out of 54 total transcripts. A score of at least 80% agreement is

required to ensure reliability of the data. Overall interrater reliability was 85.2% agreement, ranging from 80% to 93%.

RESULTS

The descriptive analysis of the participant data, including the means and standard deviations of all dependent variables for all 6 participants, is shown in Figure 3.

Figure 3: For all 6 participants, means and standard deviations of all dependent variables.

	Text						
	Total Utterances	M	NR	NU	P	E	O
Mean	29.10	8.22	10.27	0.56	0.89	0.44	7.61
SD	10.20	0.91	5.58	0.69	0.83	0.93	2.74
	Pictures						
	Total Utterances	M	NR	NU	P	E	O
Mean	31.30	0.00	14.50	1.94	1.11	1.61	12.11
SD	14.40	0.00	6.99	1.94	0.89	3.79	6.90
	Combined						
	Total Utterances	M	NR	NU	P	E	O
Mean	35.30	5.39	16.62	1.61	1.33	1.06	9.33
SD	12.90	1.99	7.09	1.51	2.21	1.97	5.61

The descriptive analysis of the partner data which includes means and standard deviations of all 3 dependent variables for the partner in all sessions is shown in Figure 4.

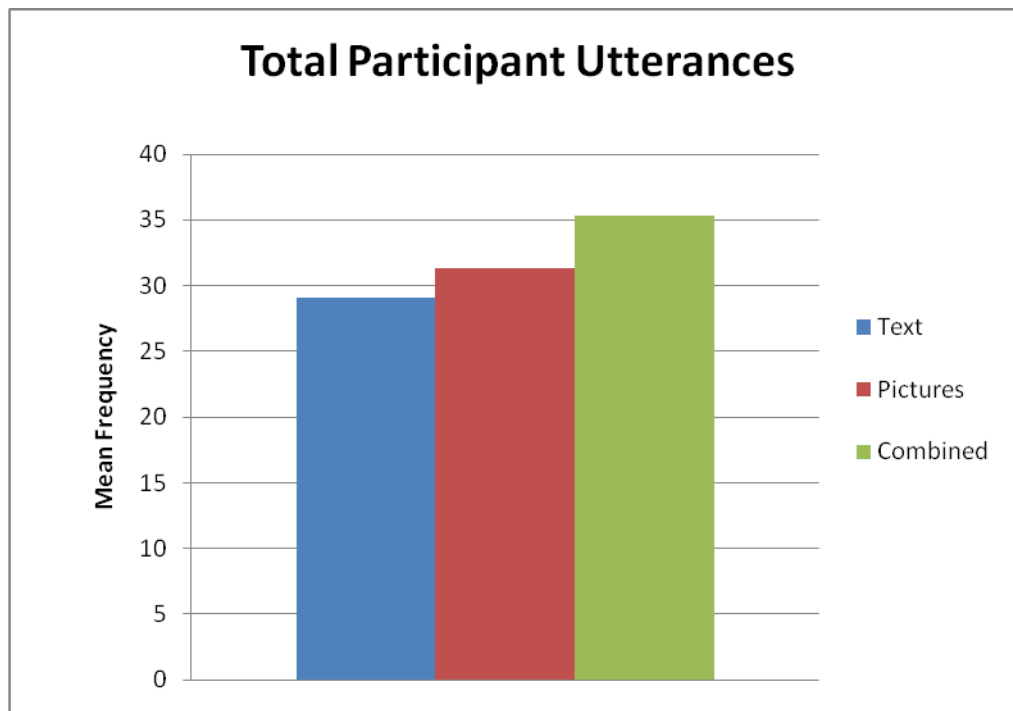
Figure 4: For the 3 partner dependent variables, means and standard deviations.

	Text			
	Total Utterances	PP	PS	PO
Mean	12.22	3.89	0.64	7.70
SD	2.94	1.80	0.82	2.48
	Pictures			
	Total Utterances	PP	PS	PO
Mean	15.53	3.58	2.64	9.31
SD	4.72	0.97	1.83	4.09
	Combined			
	Total Utterances	PP	PS	PO
Mean	15.83	4.61	1.69	9.53
SD	3.64	1.89	1.56	2.40

Analysis of Participant Data

To answer the research question of which stimulus contributed most to conversations, the total number of utterances was analyzed as shown in Figure 5. The text condition had an average of 29.1 utterances with a standard deviation of 10.2. The picture condition had an average of 31.3 utterances with a standard deviation of 14.4. The combined condition, comparatively, had the highest average at 35.3 utterances with a standard deviation of 12.9. The Repeated Measures ANOVA of the mean number of Total Utterances elicited from subjects was statistically significant [$F(1,5) = 6.67$; $p < .05$]. The Bonferroni post-hoc comparisons did not reveal any significant differences between any of the stimulus conditions.

Figure 5: Total Participant Utterances



The mean total number of Memory Book Statements elicited from the participant in each condition are shown in Figure 6. The mean for the text alone condition was 8.22 with a standard deviation of .91. The mean for the picture condition had a mean of 0.00 because there was no text in this condition. The mean for the combined condition was 5.39 with a standard deviation of 1.99. The means were statistically different [$F(1,5) = 18.45$; $p < .01$]. The Bonferroni post-hoc comparison revealed differences between the text and picture conditions ($p > .001$), picture and combined conditions ($p = .004$) and between the text and combined conditions ($p = .023$).

Figure 6: Memory Book Statements

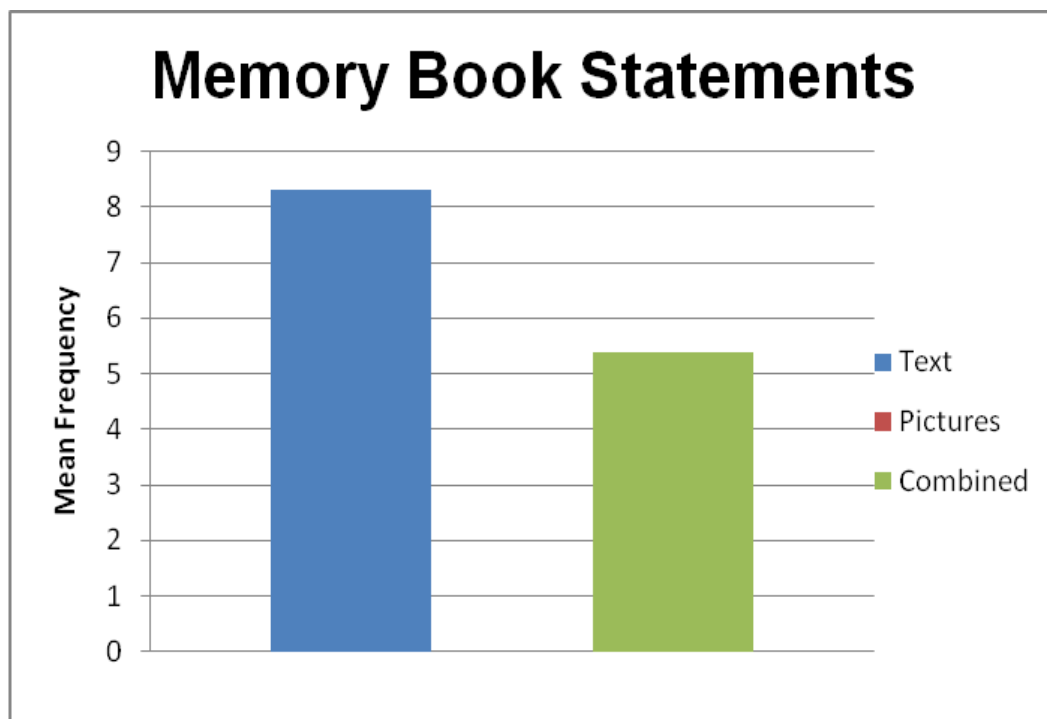
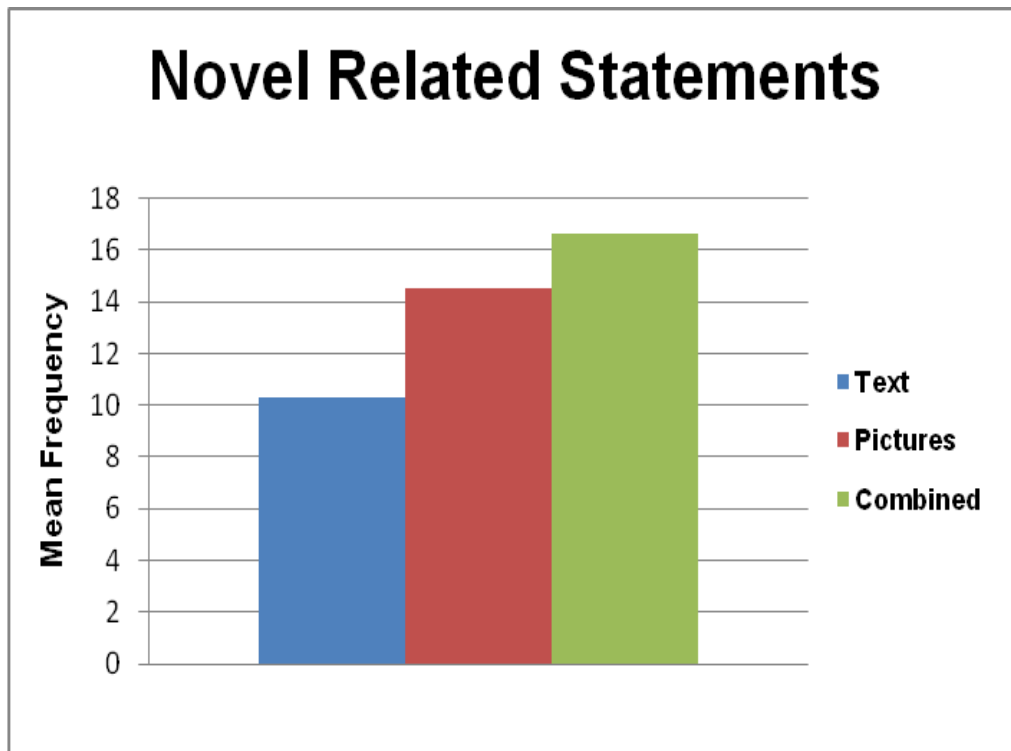


Figure 7 illustrates the means of the Novel Related Statements elicited from the 6 participants. With a mean of 10.3 and a standard deviation of 5.6, the text condition elicited the least Novel Related Statements when compared to the other two conditions. The picture condition elicited more Novel Related Statements than the text condition with a mean of 14.5 and a standard deviation of 6.9. Eliciting the most Novel Related Statements was the combined

stimulus condition with a mean of 16.6 and standard deviation of 7.1. The means for the total number of Novel Related Statements elicited from the participants were statistically different [$F(1,5) = 10.26$; $p = .024$]. The Bonferroni post-hoc comparison revealed that the means of the text condition and the combined condition were not significantly different ($p = .072$). The other comparisons were not statistically different either.

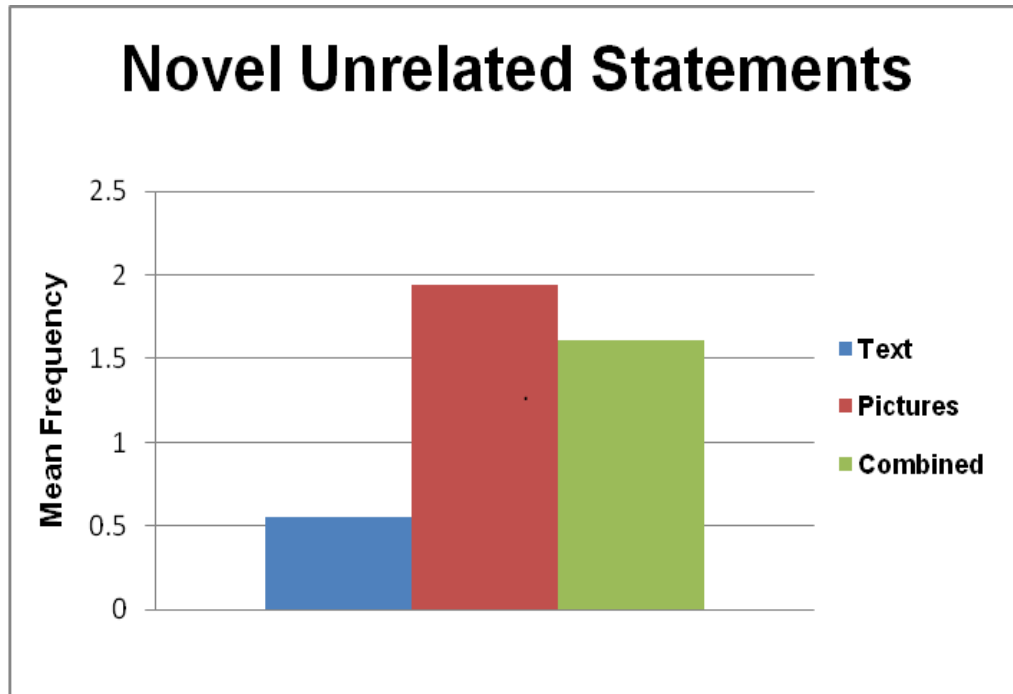
Figure 7: Novel Related Statements



The mean Novel Unrelated Statements for each condition are shown in Figure 8. The mean Novel Unrelated Statements for the text condition was .56 with a standard deviation of .69. The mean for the picture condition was 1.94 with a standard deviation of 1.94. The combined stimulus had a mean of 1.61 with a standard deviation of 1.51. The means were not statistically different [$F(1,5) = 2.05$; $p = .212$]. The Bonferroni post-hoc comparison revealed no significant

difference between any of the conditions. It should be noted that, on average, fewer than 2 Novel Unrelated Statements were produced in any conversation.

Figure 8: Novel Unrelated Statements – Participants



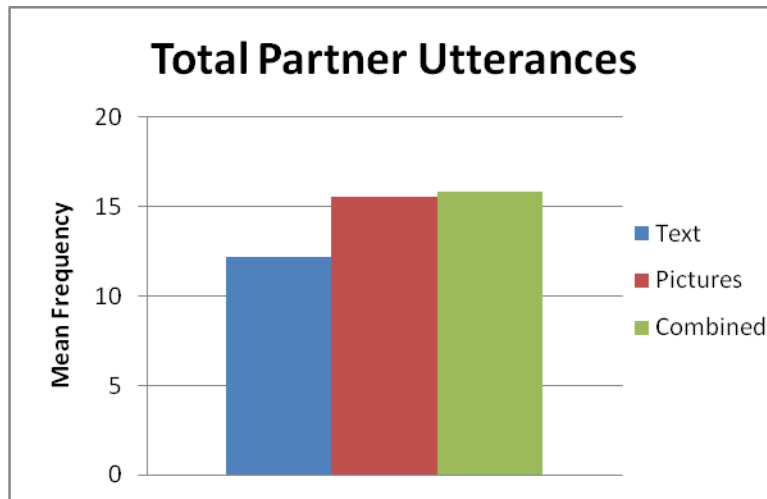
As shown in Figure 3, the other dependent variables (perseverative statements and error statements) were similarly low frequency behaviors. The Other Statements category had mean frequencies of 7.6 (text), 12.1 (pictures), and 9.3 (combined), respectively. However, there were no statistical differences among conditions for these variables.

Analysis of Partner data.

The means for the total number of Partner Utterances, Partner Prompts, Partner Statements, and Partner Others were examined in order to ensure that the partner was not ‘helping’ one subject more than another in any of the 3 conditions. The distribution of total Partner Utterances was relatively similar for all 6 participants as shown in Figure 9. The mean total number of Partner Utterances in the text condition was 12.22 with a standard deviation of

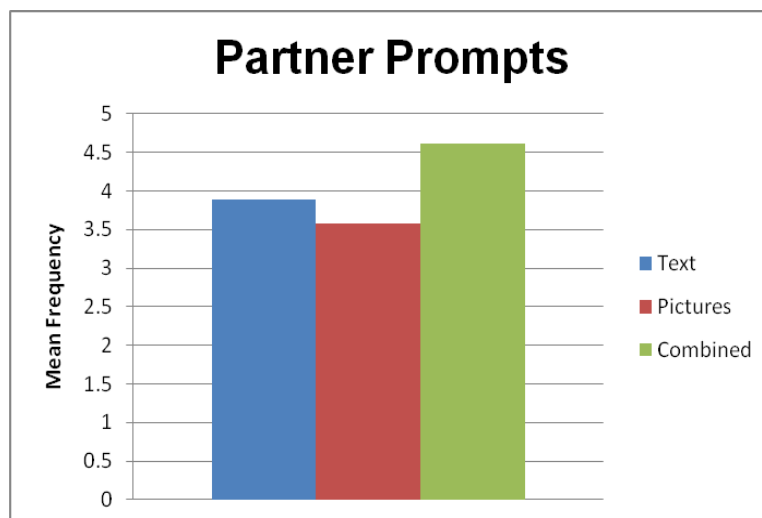
2.94. The mean in the picture condition was 15.53 with a standard deviation of 4.72. The mean in the combined condition was 15.83 with a standard deviation of 3.64.

Figure 9: Total Partner Utterances



As shown in Figure 10, Partner Prompts varied between conditions but never exceeded 5 per 5-minute conversation. The mean Partner Prompts for the text condition was 3.89 with a standard deviation of 1.79. The mean for the picture condition was 3.58 with a standard deviation of .97. The mean for the combined stimulus was 4.61 with a standard deviation of 1.88.

Figure 10: Partner Prompts



The statistical analysis revealed that the means were not significantly different for any of the dependent variables for the partner: Total Partner Utterances, Partner Prompts, Partner Statements, and Partner Other Statements. This confirms that the experimenter was consistent in each condition and between participants. Because the means were not statistically significant, the Bonferroni post-hoc comparison was not completed.

DISCUSSION

The purpose of this study was to examine the relative benefits of different types of stimuli presented in a Memory Book. In previous research, the use of a Memory Book with a combined stimulus gave those with dementia the most opportunity and potential to talk about different topics in the Memory Book (Bourgeois, 2007). The results of the current study revealed that the combined condition produced significantly more Total Utterances overall and more Novel Related Statements than either separate condition. The text alone condition produced more Memory Book Statements than either of the other two conditions; and the picture alone condition produced more Novel Unrelated Statements and Other Statements than the other two conditions. There were no significant findings for the categories of Perseverative, Error, or Other Statements. Similarly, there were no significant differences in the number of Total Partner Utterances, Partner Prompts, Partner Statements, and Partner Other Statements and across stimulus conditions.

Previous studies of the effects of Memory Books on conversation compared a combined stimulus to a non-stimulus condition and showed that the combined stimulus produced more statements of fact and fewer ambiguous and error statements than a condition without a Memory Book (Bourgeois, 1992a; 1992b). These studies documented statistical differences between conditions because the comparison was between a stimulus with cueing and a stimulus

completely without cueing. The current study confirmed that, as in previous studies using combined stimuli, the combined stimulus condition allowed participants to talk more (Total utterances) and to generate more Novel Related Statements than either separate condition. This finding suggests that clinicians and families should be advised to use both picture and text stimuli when making Memory Books.

The text alone condition produced more Memory Book Statements than either of the other two conditions. Previous research has not investigated the use of text alone to elicit conversation in persons with dementia. Therefore, this finding suggests that when presented with text only persons with dementia will read the text, but not necessarily be able to use that information to trigger other related memories.

The picture alone condition produced more Novel Unrelated Statements and Other Statements than the other two conditions. As with text alone, previous research has not investigated the use of only pictures to elicit conversation in persons with dementia. A possible explanation for why the picture condition produced more Novel Unrelated and Other Statements is that the participant was trying to retrieve a memory on their own without sufficient cueing and they talked about anything that came to mind even if it was not related to the picture. Although Other Statements occurred with a higher frequency in the picture only condition, there were no significant differences among conditions. Included in this category are statements such as, “I don’t remember”, “Okay”, “Can you hand me a tissue?” It is possible that these results were due to the fact that each condition in this study had some sort of stimulus cueing. In previous research, Bourgeois (1990, 1992) documented significant reductions in the frequency of ambiguous, error, perseverative, and other utterances when participants used a memory book compared to when they did not have a book at all. This might also explain why the other

dependent variables, Perseverative Statements and Error Statements, were not statistically different in this study. Perseverative Statements and Error statements were low in frequency in all conditions (both less than 2 on average).

Only one dependent variable, Novel Unrelated Statements demonstrated unexpected results in the picture only condition. Novel Unrelated Statements were elicited the most when a picture stimulus was presented, and the least when a text stimulus was presented. The picture condition yielded more Novel Unrelated Statements than the other two conditions possibly due to the subject having no supporting information in the Memory Book to assist them. The text condition yielded the fewest Novel Unrelated Statements than the other two conditions possibly due to the subject merely reading the statement printed in the Memory Book. Note that for all 3 conditions fewer than two Novel Unrelated Statements were elicited.

The fact that all partner dependent variables did not yield any significant differences among conditions confirmed that the researcher was correctly following the research protocol of minimally prompting and commenting, thus allowing the participant to do the majority of the talking. These were the same procedures that were used by Bourgeois in the previous Memory book studies (1990, 1992) and thus allows for the results of this study to be compared with those studies. Partner statements included utterances that added something to the conversation such as a response to a participant's question to the experimenter, "Do you have any children?" after they had read a page in their Memory Book and had talked about their family members. Partner statements averaged fewer than 3 statements per 5 minute conversation, and were not significantly different across conditions. The category of Partner Others was similar to the category of Other Statements used by the participants in that this category of utterances did not add any new content to the conversation, mostly consisted of reassurances, acknowledgments

and statements to regulate the flow of conversation, and was not significantly difference across conditions.

Limitations

The limitations of this study are related to the number and type of participants. This was a small N study investigating the conversations of only 6 participants with moderate dementia. More participants would be needed to generalize the findings of this study to the larger population of patients with dementia. Similarly, participants with a wider range of dementia severity would be needed to be able to generalize the findings of this study to the larger population of persons with dementia. It would be important to replicate this study with more participants having a range of dementia severity.

Future Studies.

The goal in the future is to improve memory aids and strategies for older adults with dementia in order for them to have better conversations and a better quality of life. Expanding this study to more individuals and to individuals with more variety of dementia severity would be beneficial for external validity purposes. The current study, however, not only helps those in the future who may need a memory aid with the optimum stimulus characteristics, but it also was thought to benefit the participants of this study. After the study was completed each participant was made an expanded Memory Book, including more than the ten-pages used in the study. Each participant also had many opportunities throughout the study to converse with another individual other than a family member or caregiver using the Memory Book. Because of the study, the participant has a Memory Book that they can refer to often and use to supplement their conversations. Additionally, the family member or caregiver may have learned about the use and benefits of the Memory Book and hopefully they will help the individual with dementia to use it

in conversations and other situations. Furthermore, a follow-up study with the participants of this study may be appropriate in the future. It would examine the use of the Memory Book after the study was completed. Possible variables to consider would be caregiver or family member reflections (a survey or interview), the amount that the subject used the Memory Book after the study, and if there is a significant difference between the data collected in this study and in the future.

Conclusions

Because previous Memory Book research investigated the use of a combined (pictures and text) stimulus only, there has been little evidence for the relative benefits of each stimulus individually. Many studies have examined the effects of Memory Books on conversation (Bourgeois, 1992, 1992a, 1992b). Each study focused on a different aspect of conversation or format of the Memory Book, but all used a combined stimulus of pictures and text. The assumption that a combined stimulus in a Memory Book would benefit individuals the most can now be supported by the data collected in this study.

This study described the differences in effectiveness of different stimuli (text, pictures, combined) in a Memory Book. It can be used to help other professionals or family members create a Memory Book or aid that is the most beneficial to the individual with dementia. Based on the results, a combined stimulus is believed to be the most effective in eliciting and supporting conversations in dementia.

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APPENDIX A

The Ohio State University Consent to Participate in Research

Study Title: The Effects of Print and Picture Stimuli on Conversation in Dementia

Researcher: Michelle S. Bourgeois, PhD

Sponsor: None

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose:

The purpose of this research is to determine the effects of print stimuli, picture stimuli, and combined (print + picture) stimuli on the conversational content of persons with dementia.

Procedures/Tasks:

Twenty subjects (male and female; 65-85 years) with dementia will be identified at various locations (e.g., Laurel Nursing Homes) by staff at those facilities. Proxy consent for participation in the study will be solicited from a family member or legal representative and the person with dementia will be asked to assent to the study. After consent and assent are obtained, the investigators will meet with the individual to administer two measures: 1) the Mini Mental Status Examination (Folstein, Folstein, & McHugh, 1978) and 2) the Bourgeois Oral Reading Screen (Bourgeois, 1994); family members will be asked to complete the Memory Book Information Short Form (Bourgeois, 1994) and to provide pictures for 12 of the statements. The investigators will then create three memory books for each participant: one with pictures, one with text, and one with both pictures and text. On each of three days, participants will be asked to have 5-min conversations about their life and family using one of the three versions of the Memory Book, counterbalanced for order within each session (for a total of 9 conversations). Each session will begin with a conversation, followed by a ten minute distraction task (distractions include: taking a walk, eating a snack, reading a book, making a puzzle, etc.), a second conversation, followed by a second ten-minute distraction task and the final 5-min conversation (for a total of 35 minutes per session). The initial screening protocol should take no longer than 60 minutes to administer. At any time if the participant expresses fatigue or disinterest in the procedures, the session will be discontinued. Each participant will be visited on four separate occasions (1 screening and 3 conversational sessions). All sessions will be audio-taped for analysis.

Duration:

You may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

Risks and Benefits:

The purpose of this study is to determine which type of stimuli is better for supporting conversation of the participants about their life, living conditions, family members, and other personal topics, many of which could be sensitive or embarrassing. Therefore, some participants could consider the questions posed in the protocol as an invasion of their privacy. If a participant expresses, either verbally or nonverbally, that they are confused, suspicious, reluctant, or unwilling to engage in conversation with the PI, the session will be terminated immediately. It is the experience of the PI that these expressions of discomfort are rare and easily resolved by terminating the session. The PI will notify the staff or family member immediately after terminating a session, in order that the appropriate support measures are implemented to resolve any negative ramifications of the session.

The direct benefit to participants is that they will receive individualized attention, including opportunities to converse with the investigator, and that may be pleasurable for them. The benefit to others includes providing health care professionals with insight into the nature of decline of cognitive function in dementia

Confidentiality:

Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives:

You will not be paid for your participation in this study.

Participant Rights:

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study you may contact:

Michelle S. Bourgeois, Ph.D., CCC-SLP, (614) 292-1742.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact: **Michelle Bourgeois, Ph.D., (614) 292-1742.**

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

<hr/> Printed name of subject	<hr/> Signature of subject
	<hr/> Date and time
	AM/PM
<hr/> Printed name of person authorized to consent for subject (when applicable)	<hr/> Signature of person authorized to consent for subject (when applicable)
	<hr/> Date and time
	AM/PM
<hr/> Relationship to the subject	

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

<hr/> Printed name of person obtaining consent	<hr/> Signature of person obtaining consent
	<hr/> Date and time
	AM/PM

APPENDIX B

Memory Book Study Protocol

Subject Name: _____
 Address: _____
 Caregiver Name: _____
 Relationship: _____
 Caregiver Address: _____
 Caregiver Phone: _____

Subject Demographic Information:

Date of Birth: _____
 Race: _____
 Gender: _____
 Education: _____

I. Screening Measures:

a. functional vision, hearing, and communication screening measures
 (Bourgeois et al., 2001)

VISION (from Minimal Data Set 2.0)

(Ability to see in adequate light and with glasses if used)

0. ADEQUATE – sees fine detail, including regular print in newspapers/books.

1. IMPAIRED - sees large print, but not regular print in newspapers/ books.

2. MODERATELY IMPAIRED- limited vision; not able to see newspaper headlines, but can identify objects.

3. HIGHLY IMPAIRED – object identification in question, but eyes appear to follow objects.

4. SEVERELY IMPAIRED - no vision or sees only light, colors, or shapes; eyes do not appear to follow objects.

VISUAL LIMITATION/ DIFFICULTIES

a. Side vision problems – decreased peripheral vision(e.g., leaves food on side of tray, difficulty traveling, bumps into people and objects, misjudges placement of chair when seating self).

b. Experiences any of following: sees halos or rings around lights; sees flashes of light; sees curtain over eyes.

c. NONE OF ABOVE

VISUAL APPLIANCES

Glasses; contact lenses; magnifying glass

0. No 1. Yes

HEARING

(With hearing appliance, if used)

- 0. Hears adequately – normal talk, TV, phone
- 1. Minimal difficulty – when not in quiet setting
- 2. Hears in special situations only- speaker has to adjust tonal quality and speak distinctly
- 3. Highly impaired – absence of useful hearing

COMMUNICATION DEVICES/ TECHNIQUES

(Check all that apply during last 7 days)

- a. Hearing aid present and used
- b. Hearing aid, present and not used regularly
- c. Other receptive communication techniques used (e.g., lip reading)

COMMUNICATION**5 MINUTE CONVERSATION**

Set stopwatch for 5 minutes. Prompt at 3.5 and 2.0 minutes approximately. If necessary, use other general prompts (“tell me more” or “what else can you tell me about your life, family, etc.”).

- 1. Tell me about your family. _____
- 2. Tell me about your life. _____
- 3. Tell me about your day. _____

Rating of Responses

- 1 No verbal or vocal response to interviewer.
- 2 Unintelligible verbal responses, or vocalizing only.
- 3 Single word responses, includes yes/no responses.
- 4 Phrases, multiword only.
- 5 Single sentences only.
- 6 Elaborated conversation; multiple sentence responses; appropriate, normal conversation.

II. MINI – MENTAL STATE EXAMINATION (Folstein, Folstein, & McHugh, 1975)**1. Please tell me today’s date.**

1.1 What month is it? _____

1.2 What date is it? _____

1.3 What year is it? _____

1.4 What day is it? _____

1.5 What season is it? _____

1.6 Score (Maximum score = 5) _____

2. Please tell me where we are in right now?

2.1 building _____

2.2 floor _____

2.3 city _____

2.4 county _____

2.5 state _____

2.6 *Score*(Maximum score = 5) _____

3. **I'm going to name three objects and I'd like you to repeat them after me.**
(Name three objects, allowing one second to say each one.)

Apple . . . Table. . . Penny

Give 1 point for each correct answer on the first trial only. Repeat the objects until the patient can name them all (maximum of 6 trials). Stop after 6 unsuccessful trials and enter a 7 for number of trials to indicate that they never learned the succession.

3.1 # of Trials _____

3.2 *Score* (Maximum = 3) _____

4. **I'm going to ask you to do some subtraction. Think of the number 7. I want you to subtract 7 from 100. Now subtract 7 from that number and keep going until I stop you.**
(Enter numbers given by respondent below)

4.1.1 _____ (93)

4.1.2 _____ (86)

4.1.3 _____ (79)

4.1.4 _____ (72)

4.1.5 _____ (Stop) (65)

4.1.6 *Score* (Maximum Score = 5) _____

- 4.2 **I want you to spell a word forward and then backward. The word is 'WORLD'.**

4.2.1 **Spell it forward.** _____

(Write exact letters given by respondent in blanks.)

(If incorrect, stop and record zero for score)

4.2.2 **Spell it backward.** _____

(Write exact letters given by respondent in blanks.)

4.2.3 *Score*(Maximum Score = 5) _____

5. **Do you remember a few minutes ago, I had you repeat some words after me?**

6. **Tell me what they were?** (Give 1 point for each correct answer.)

Score(Maximum Score = 3) _____

6. **Please name these for me.**

(Show the client a wooden pencil and a watch, preferably worn on the wrist.

Score 1 point for each correct answer.)

_____(pencil)

_____(watch)

Score (Maximum Score = 2) _____

7. **I'm going to read a sentence and I want you to repeat it after me. Say exactly what I say.**

8. (Score 1 point only if every word repeated correctly.)

NO IFS, ANDS, OR BUTS. _____

7.1 Score(Maximum score = 1) _____

8. **Read this card and do what the card tells you to do.**

(Show the card with "Close your eyes" on it. One prompt allowed after initial instructions.

Score 1 point. You may need to tell them to open their eyes.)

8.1 Score (Maximum score = 1) _____

9. **Now I'm going to ask you to do something for me. I'm only going to say it once, so listen carefully. Score 1 point for each step.**

Take this paper in your right hand; _____

Fold the paper in half with both hands; _____

And put the paper in your lap. _____

9.1 Score (Maximum score = 3) _____

10. **Now, please write a sentence for me on the piece of paper.**

(Do not dictate a sentence or provide a subject; it must be written spontaneously.

The sentence must contain a subject and verb and be sensible.

Correct grammar and punctuation not necessary. Score 1 point.)

10.1 Score (Maximum = 1) _____

11. **Please copy this design exactly as it is for me.**

(Hold the card with the design on it in front of the client; do not let the client trace the design.

All 10 angles must be present, and 2 must intersect to score 1 point.

Tremor and rotation are ignored.)

11.1 Score (Maximum = 1) _____

12. Did the client exhibit any signs of illiteracy, or of physical impairments that would hinder performance on any of the items in this test? (*Do not include this score in the MMSE total score.*)

() No

() Yes

If yes, please specify: _____

MMSE TOTAL SCORE (Maximum = 30) _____

III. Oral Reading and Comprehension (Bourgeois, 1994) (Total Score Possible: 24)

(*Circle words that are spoken intelligibly; 1 point for each word read correctly and 1 point for each concept understood.*)

(*If patient says he cannot see the words, start with Large print stimuli*)

(*If patient says he cannot read, ask him to talk about the picture.*)

Instructions: Please read this page and tell me about it.

Small Print:	Oral Reading	Comprehension
--------------	--------------	---------------

The dog's name is Rover. (5 possible)	_____	_____
---------------------------------------	-------	-------

I live in Swissvale. (4 possible)	_____	_____
-----------------------------------	-------	-------

I enjoy baseball games. (4 possible)	_____	_____
--------------------------------------	-------	-------

My sister is 75 years old. (6 possible)	_____	_____
---	-------	-------

His wife's name is Mary. (5 possible)	_____	_____
---------------------------------------	-------	-------

(Add points above): Oral Total	_____	Comprehension Total: _____
--------------------------------	-------	----------------------------

(*If 5 or more words are in error, repeat test with large print stimuli; 1 point for each word.*)

Comment about other reading behaviors (e.g., needed prompts to turn pages; put booklet up to face to read; needed prompts to read out loud; claimed inability to read/see, etc.)

Large Print:	Oral Reading	Comprehension
--------------	--------------	---------------

The dog's name is Rover. (5 possible)	_____	_____
---------------------------------------	-------	-------

I live in Swissvale. (4 possible)	_____	_____
-----------------------------------	-------	-------

I enjoy baseball games. (4 possible)	_____	_____
--------------------------------------	-------	-------

My sister is 75 years old. (6 possible)	_____	_____
---	-------	-------

His wife's name is Mary. (5 possible)	_____	_____
---------------------------------------	-------	-------

(Add points above): Oral Total	_____	Comprehension Total: _____
--------------------------------	-------	----------------------------

Comment about other reading behaviors (e.g., needed prompts to turn pages; put booklet up to face to read; needed prompts to read out loud; claimed inability to read/see, etc.)

IV. Memory Book Information Form (for family members)

Please complete the following sentences which you think would be most appropriate for your family member and for which you have a picture to use in the Memory book.

1. My name is _____ (full name or nickname)
2. I was born on _____ in _____ (city, state)
3. My parents were _____ (names)
4. I spent most of my career working for _____
5. My wife's/husband's name is _____
6. Our wedding was on _____ (date) in _____ (city, state).
7. My children's names are
 a) _____ b) _____ c) _____ d) _____ e) _____
8. What are the current occupations of these children (or their spouse's name)?
 a) _____ b) _____ c) _____ d) _____ e) _____
9. My grandchildren's names are
 a) _____ b) _____ c) _____ d) _____ e) _____
10. My _____ (type of pet)'s name is _____.
11. I went to college/high school at _____ in _____ (city, state).
12. I earned a living _____ (my occupation).
13. Now that I am retired I enjoy _____.

14. I used to play _____ (sport/instrument)

15. My favorite pastime is/was _____ (hobby)

16. When I was younger I used to _____ (anything)

17. I attend (went to) _____ (church/temple).

18. One of my most memorable vacations was _____ (where), on
_____ (when), with _____ (with whom).

Anything else that is particularly important or memorable:

19. _____

20. _____

APPENDIX C

Data Coding Sheet

Subject (S): _____ Partner (P): _____
 Session: _____ Date: _____

	S	P		S	P		S	P
1			31			61		
2			32			62		
3			33			63		
4			34			64		
5			35			65		
6			36			66		
7			37			67		
8			38			68		
9			39			69		
10			40			70		
11			41			71		
12			42			72		
13			43			73		
14			44			74		
15			45			75		
16			46			76		
17			47			77		
18			48			78		
19			49			79		
20			50			80		
21			51			81		
22			52			82		
23			53			83		
24			54			84		
25			55			85		
26			56			86		
27			57			87		
28			58			88		
29			59			89		
30			60			90		

TOTALS:

	Subject
M	
NR	
NU	
P	
E	
O	

	Partner
PP	
PS	
PO	